

Competition in Medical Ethics

The journal's latest competition was based on the case history and questions which follow. Entries were to be between 1500 and 3500 words and were judged mainly by the quality of the arguments supporting whatever positions were put forward in the light of relevant counterarguments to those positions. Manifest awareness of the relevance of different perspectives was one of the criteria for judging the entries.

The paper which follows is the winning entry and the author will receive the £100 prize.

Case-history

During your morning general practice surgery a 50-year-old woman sees you, complaining of some mild clumsiness and of worsening memory. In the course of your examination of her mental abilities you find some slight evidence of memory difficulty. You take a sample of blood for a number of basic investigations. Towards the end of the consultation she tells you that she is frightened that these symptoms are due to Huntington's chorea. She then tells you that her father, and his mother both died in their fifties from this disease. The rest of her family do not know of the occurrence of Huntington's chorea in her relatives. She

insists that you do not tell them and she also forbids you to let them know of her present concerns.

Later that morning this woman's daughter sees you to discuss coming off the contraceptive pill as she and her husband wish to conceive a child. During the course of the consultation she tells you that her younger sister, who is a patient of another general practice, is also thinking of starting a family.

Questions to be considered

What do you say to the daughter?

How do you reconcile your desires to respect the mother's confidences, to give the daughter information of importance to her decision about conceiving a child, and to fulfil your duty of care to both patients?

Do you have responsibilities to both daughters? If so how should you implement your responsibility to the younger daughter?

Should you use some of the blood taken from the mother for genetic testing on the grounds that you may be able then to find out whether the daughter carries the Huntington gene?

Do the mother's memory difficulties affect your decisions?

Competition in medical ethics

Confidentiality and Huntington's chorea

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Author's abstract

A doctor has duties towards his patients of both confidentiality and veracity and at times these may conflict, as in the following case. A mother who has the symptoms of Huntington's chorea does not wish her daughters to know. The doctor must try to make her realise how valuable the information can be to the daughters, and thus obtain her consent to inform them. If the mother's consent cannot be obtained, then the doctor must tell the mother that he cannot allow her attitude to deprive the daughters of this information, especially at this crucial time as they plan to have children. The well-being of the daughters' future families must take precedence over the mother's desire for secrecy regarding her condition.

There are two broad ethical issues which have to be faced frequently by health care professionals: telling the truth to patients and confidentiality. Are there any circumstances in which it is justifiable for a doctor to lie to a patient? Can a patient expect the doctor to keep in absolute confidence any information that she divulges to him? In the final analysis both of these matters must be an individual decision, but there are some overall principles which should influence each particular decision.

The duty of veracity

Doctors are usually thought of as model citizens. Outside the field of health care, the doctor is classed amongst those whose signature on a document can verify its worthiness, alongside lawyers and clergymen. The British Medical Association states that the relationship between the patient and the doctor is based on trust and that clear communication is of fundamental importance, but the following excerpt is the nearest it comes to pledging the doctor to truthfulness:

'The doctor must choose his words with care, not only to ensure that the patient is provided with an unambiguous reply to the questions posed during the

diagnostic process, but also to ensure that no misunderstanding occurs in giving any information to the patient concerning his condition, the régime of treatment proposed (with side effects explained where appropriate) and also the prognosis' (1).

This could certainly be taken to imply honesty, and without truthfulness the trust in a relationship will soon be lost. Medical ethics is part of general morality and not a separate field on its own with its own special rules. Unless there are exceptional justifications, health care professionals are working within the same moral constraints as lay people. In order for any human interaction to be valuable, it must be based on the premiss that communication will be honest.

The duty of confidentiality

An obligation of confidence to patients lies at the heart of all codes of medical ethics, but the obligation is not always absolute. Whereas the Declaration of Geneva (as amended in Sydney, 1968) stated: 'I will respect the secrets which are confided in me, even after the patient has died' (2), so that any information given by a patient must be kept secret forever, the Hippocratic Oath which the Ancient Greeks took left the doctor to judge for himself to some extent what he might speak about or must keep silent about:

'Whatever, in connection with my professional practice, or not in connection with it, I see or hear in the life of men, which ought not to be spoken of abroad, I will not divulge, as reckoning that all such should be kept secret' (2).

Both types of codes cause some problems. An absolute obligation leaves the doctor powerless beyond trying to persuade the patient to divulge the information. On the other hand a relative obligation, which leaves the doctor free to breach confidence when he judges that some higher duty to another person or to society applies, may disincline patients from seeking necessary treatment. This may damage not only the patient but also those very people who are vulnerable when the doctor treats and does not 'tell'.

The *Principles of Medical Ethics* of the American Medical Association (1957), section nine, states:

Key words

Veracity; confidentiality; trust; Huntington's chorea; genetic defects.

'A physician may not reveal the confidence entrusted to him in the course of medical attendance ... unless he is required to do so by law or unless it becomes necessary in order to protect the welfare of the individual or of the community' (3).

This view can be summed up in the maxim, 'the protective privilege ends where the public peril begins', and should be considered as the guiding principle where there is a conflict between the duty of confidentiality and the duty of veracity.

Case study

The mother has presented herself for diagnosis, insisting that if she, like her father and grandmother before her, has Huntington's chorea, none of her family should be told. The doctor must immediately make clear to the mother that she cannot bind him to absolute confidentiality in a matter which may so deeply affect the lives of her children. If he is not already aware of the structure of her family, he should inquire about her children, then explain to her how the information as to whether she has Huntington's chorea could be so vital to her children in making decisions about their future offspring. The doctor has already taken a blood sample for other tests, but he has no right to have it tested for Huntington's chorea without the consent of the patient. Otherwise the patient may have a case against him in battery. In obtaining the consent for the test, the doctor must ensure the mother realises that if the test result is positive, he will feel obligated to inform the daughters. If the mother refuses, then he must respect her wishes. However, if the mother can be made to understand how valuable the information could be to her children in planning their families – whether not to have any children, to have selected abortion of affected fetuses, to have children by ovum donation or to have their own genetic children regardless of the consequences – then it is likely that the mother will consent to the blood test.

The daughters

When the daughter visits the doctor later that morning it would be far too soon to divulge the information which the mother has disclosed and which as yet is inconclusive in any case. The mother must be given time to see the value of informing the daughters, as it is much better that the information is either revealed by her or at least given with her consent. However, to allow the daughter to risk becoming pregnant before she has the information would also be a mistake. The doctor should reveal to the daughter that the mother is at present undergoing tests (without revealing the nature of the tests) which may influence the daughter's decision about pregnancy and that the mother is unwilling to discuss the situation at present. He should indicate to the daughter that he feels it would be wise for her to remain on the contraceptive pill for another couple of months, until the results of the tests are confirmed.

The older daughter will probably relay the information to the younger daughter in any case, but the doctor must fulfil his responsibility towards her by giving some information about the mother to the younger daughter's GP. How much information the doctor divulges may be influenced by how well he knows the GP. If he knows him well and feels certain his own attitude will be reflected by the GP, he may tell him the full details of the case, with the assurance that the GP will only divulge to the younger daughter what he himself has told the older one. If the GP is not well known to him or he feels the GP's views may differ from his own, then he should only give the GP the information that he gave the first daughter, to be certain the GP will divulge no more than this. Indeed the doctor cannot be sure that the GP will even divulge this much, as he may not feel it is his responsibility to do so, but the doctor has fulfilled his responsibility to the younger daughter by informing her GP. If the younger daughter, after gaining some information from her own GP or from her sister, should then decide to visit her mother's doctor, then the doctor should give her the same advice and information that he gave to the older daughter, and inform her GP that he has done so.

The blood test

The question arises as to what further steps the doctor should take if the mother refuses to have the blood tested for Huntington's chorea. The doctor should give her several weeks to change her mind. If the mother still refuses the test, then it should be made plain to her that the daughters will be given the information as it stands. Obstinacy is one of the personality changes that may occur with Huntington's chorea, but whether the mother's refusal is evidence of such a change or just her natural character, neither should prevent the doctor from fulfilling his duty within the law. If the doctor cannot persuade the mother that her attitude is selfish, then he must risk losing her trust. However, trust is usually based on truthfulness, and while the mother may not agree to the daughters being told, the doctor will not have harmed their relationship as much by being straightforward with the mother as he would by secretly telling the daughters without informing the mother that he intended to do so.

If the mother consents to the blood test and the result is negative, then the daughter can be informed that the test was negative, and that this matter can be swept from her mind entirely, presuming that the test results are conclusive. The daughter may go ahead and have children as planned. Any enquiries from the daughter as to the nature of the test should be dismissed with the mother's plea for confidentiality. Likewise the younger daughter's GP should also be given the 'all clear'. If the test results are at all dubious, then they will have to be treated much the same as if they were positive.

If the blood test results are positive, the mother must be informed first of all. Once again the doctor needs to

explain to her the gravity of the information, how for her parents spread of the disease could have been prevented only by having no children at all, whereas if blood tests reveal her children carry the disease, they may opt for either selective abortion after chorionic villus sampling or ovum donation to prevent the genetic fault from being inherited. Most individuals will opt to divulge information when they feel it can be of benefit to other people, especially their own children. It is only when they feel a diagnosis carries nothing but a sentence of deterioration and death that they will wish to conceal it. Hopefully the doctor will manage to persuade the mother to tell the daughters herself or at least give her permission for him to tell them. If the mother absolutely refuses, then the doctor must tell her that he has no option but to go against her wishes. The daughters have already had a preliminary warning that there may be some inherited illness in the family. This time the doctor must give the older daughter the full details of the inherited condition, Huntington's chorea, and explain the necessity of a blood test to determine whether or not she is also carrying the disease. He must also relay the information to the younger daughter's GP, so that he can inform her.

The law

In 1974, a judge stated the doctor's duty in matters of confidentiality thus:

'In common with other professional men, for instance a priest and there are of course others, the doctor is under a duty not to disclose, (voluntarily) without the consent of his patient, information which he, the doctor, has gained in his professional capacity, save ... in very exceptional circumstances' (4).

A breach of a medical confidence does not usually result in any monetary loss, but in indignity and distress for the patient. It is uncertain whether damages for mental distress would be awarded in an action for breach of confidence, but in any case such damages may be costly to obtain, and complaining to the General Medical Council is likely to remain the preferred remedy in cases of breach of confidence (5). The guidelines of the General Medical Council state: 'Rarely, disclosure may be justified on the ground that it is in the public interest' (6).

If a doctor cannot persuade a patient to consent to disclosure, then he must balance his duty to the patient against the risk threatening other individuals. In circumstances where there is a genuine risk of physical danger, either of injury or disease, it is doubtful that either a court of law or the General Medical Council would convict the doctor of wrongdoing if he were to disclose information in order to avert such danger.

Honesty is the best policy

What are the alternatives? The doctor could keep the mother's secret and advise the daughter to come off the

contraceptive pill, hoping the blood test results will be negative. If they are negative, then all will be well, but this is unlikely in view of the mother's symptoms. If the blood test results are positive and the daughter is already pregnant, then the doctor will have the dreadful task of telling the pregnant daughter that she may be a carrier and may have passed the genetic defect to her offspring. Otherwise he will have to keep the mother's condition a secret until, as the years pass, it becomes obvious to the daughter that there is something seriously wrong with her mother. Does the doctor then admit to the daughter, when she has her family of children, that he has known since before she ever started her family that the mother had the disease? Or does he pretend he knew nothing about it? In the end the daughter will probably have to care for the mother as the disease process takes its toll on her ability to care for herself. Surely it would be better for the doctor to have the trust of the daughter, than for her to feel, even if she does not have proof, that she has been deceived. Although there may be some initial resentment between the mother and the daughters if the doctor tells the daughter without the mother's permission – by the mother that her secret has been divulged and by the daughter that her mother should firstly carry the disease and secondly wish to conceal it from her – it will be far less than the grudge that the daughter will forever carry against the mother if she only finds out when the truth can no longer be concealed.

Conclusion

Doctors are trained to cure people and so often have difficulty dealing with an illness for which there is no cure. The two fundamental principles of doing good and not doing harm – of beneficence and non-maleficence – are the most frequently stressed by medical practitioners. One might say that the doctor would be causing the daughter unnecessary stress by warning her of some inherited disorder of which he has no proof. In other areas of life no professional would consider it his duty to suppress information in order to preserve short-term happiness. An accountant who foresaw that bankruptcy might befall his client would be considered to have failed in his duty if he did not advise on certain precautionary actions to avoid the calamity. That the bankruptcy might not occur would not be regarded as a sufficient reason glibly to ignore the issue. Surely a future child's health is of greater importance than wealth and so should deserve at least equal concern. The mother has a responsibility towards her children, and even if she chooses to ignore it, the doctor should make very clear right from her initial visit that confidentiality can never include withholding information which is of such value to someone else, either in preserving a life or in preventing a genetic defect from being inherited. Just as an infectious disease must be reported to the health authority for the good of society as a whole, so too knowledge of a genetic disease belongs to all the

offspring whose lives may be affected by it.

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 - (4) *Hunter v Mann* (1974) 1 QB 767,772.
 - (5) See reference (2): 35.
 - (6) General Medical Council. *Professional conduct and discipline: fitness to practice*. London: GMC, 1985: 20.
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